Original Paper

Design Preferences for a Digital Advance Care Planning Tool to Support People Living With Dementia: International Stakeholder Survey and Mixed Methods Analysis

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Abstract

Background: Dementia is a progressive, life-limiting condition in which decision-making capacity diminishes over time, yet advance care planning (ACP) remains predominantly framed as a documentation-focused end-of-life task. This narrow framing fails to address the iterative, stage-specific clinical needs—such as behavioral change, care transitions, and caregiver support—that, in addition to clinical symptoms, characterize the full dementia trajectory. Although digital ACP (dACP) tools offer potential for integrating ACP with early palliative care principles, no study has systematically derived stakeholder-informed design priorities spanning ACP content, caregiver functionality, health system interoperability, and review frequency within a multigroup framework.

Objective: This study aims to identify and prioritize stakeholder-defined components and digital features for dACP and to examine whether priorities differ across people with dementia, informal caregivers, and health care professionals.

Methods: A cross-sectional mixed methods online survey was administered via Prolific (January-February 2025) to 232 participants: 13 people with dementia, 106 informal caregivers, and 113 health care professionals. Participants rated 12 dementia-tailored ACP content elements and 10 caregiver-support features on a 7-point Likert scale, indicated preferred care-plan review frequency, and rated the importance of health system integration. Open-ended responses were analyzed using large language model (LLM)–assisted thematic analysis (Anthropic Claude Sonnet 4) with subsequent dual-coder manual verification. Dimensionality reduction was performed via principal component analysis (PCA; direct oblimin rotation); intergroup differences were assessed by one-way ANOVA, and associations among central variables were assessed by Spearman correlations.

Results: The final sample included 232 participants. PCA identified 2 interrelated ACP domains—Comprehensive Care Planning and End-of-Life Preparation and Active Disease Symptom Management—and a caregiver domain capturing Caregiver Stress Management. Across items, strategies for maintaining quality of life as dementia progresses received the highest ratings. Tips for managing challenging behaviors were the highest-rated caregiver-support feature. Participants also rated integration with existing health care systems as highly important and were in favor of context-aware, regular plan review. Qualitatively, decision-making support and guidance, communication/information sharing, and documentation/record-keeping were the most frequently cited primary purposes of a dACP tool across all groups.

Conclusions: Across stakeholder groups, priorities converged on a dACP tool centered on quality-of-life support, active symptom management, caregiver guidance, and health system interoperability. The significant interdependence of symptom-management, caregiver-support, and integration domains supports the design of a unified adaptive platform rather than discrete modules. These empirically derived priorities provide actionable design targets for an integrated dACP tool extending early palliative care in dementia from diagnosis onward.

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Keywords: dementia; advance care planning; digital health; co-design; mixed methods

Introduction

Dementia is characterized by a progressive decline in decision-making capacity accompanied by evolving care needs, which narrows the window during which individuals can meaningfully participate in future care planning. In contrast to other chronic conditions, the cognitive trajectory of dementia extends the scope of relevant care planning beyond conventional advance directives to encompass the broader spectrum of palliative care needs [1-5]. Advance care planning (ACP) is intended to align care delivery with patients' values and preferences [6]. However, in the context of dementia, ACP must additionally accommodate evolving symptomatology, the progressive transfer of decisional responsibility to caregivers, and iterative review as circumstances change [7]. The conventional framing of ACP as an end-of-life documentation exercise is therefore particularly limiting in dementia, given that its nonlinear disease trajectory requires people with dementia, family members, and health care professionals to make recurring decisions regarding safety, behavioral change, symptom burden, and the appropriate timing of supportive or palliative interventions [8]. Consequently, a dementia-specific digital ACP (dACP) tool may need to integrate conventional anticipatory planning with continuous, stage-appropriate, person-centered guidance [9,10].

ACP is widely recognized as central to ensuring that health care delivery reflects the wishes of patients and their families [11], and its relevance extends to any individual with a life-limiting illness rather than being restricted to end-of-life decision-making [12-15]. For people living with dementia, the limitations inherent to conventional, documentation-oriented ACP are compounded by the prolonged and uncertain disease trajectory and the progressive loss of communicative and decisional capacity [16], necessitating an approach capable of supporting iterative, values-based decision-making across the disease course rather than end-of-life preparation alone [15,17,18]. Thus, the focus must shift from prolonging life at any cost to enhancing the quality and meaning of the time remaining [19,20]. This perspective is consistent with the principles of early palliative care, as it encompasses comprehensive symptom management, psychosocial support, and quality-of-life care started at diagnosis and in parallel with life-prolonging measures [21-23]. The approach is well established in oncology but remains comparatively underdeveloped in dementia, where palliative input is typically introduced only during the terminal stages of illness [24-29]. Existing evidence on ACP in dementia indicates consistent improvements in process-related outcomes, although effects on quality of care and quality of life remain mixed [12,30,31], and dementia continues to be frequently misclassified as a normative feature of aging rather than a terminal condition, contributing to the under-recognition of supportive care needs [32]. Most existing interventions consequently prioritize end-of-life directives over the comprehensive, longitudinal support model established in oncology [28,33,34]. To date, no dementia-specific digital tool has been designed to address this continuum by integrating anticipatory planning, ongoing symptom management, and caregiver support.

Digital health technologies offer a potential mechanism for addressing this gap by enabling structured elicitation of patient values and preferences, facilitating communication with care teams, and prompting timely review as clinical circumstances evolve [35-38], while also accommodating disease progression through ongoing symptom assessment, care coordination, and sustained caregiver support [39-41]. However, existing digital tools remain largely fragmented and have generally been developed without systematic, stakeholder-informed prioritization of features, raising the risk that development efforts emphasize technical feasibility over end user value and usability [35,42,43]. Given the individualized and evolving nature of dementia care needs, co-creation involving people with dementia, informal caregivers, and health care professionals is essential, as top-down design approaches are unlikely to reflect the lived and shifting experience of cognitive decline [44-48]. Lived experience is, however, fundamental to effective palliative care and meaningful ACP [49,50]. To date, no study has systematically elicited and prioritized the full range of content areas and digital features required for a trajectory-spanning, dementia-specific dACP tool, a gap that the present study directly addresses. Moreover, despite significant developments in the field, few dementia-specific digital interventions integrate anticipatory planning, ongoing symptom management, caregiver support, and cross-setting communication within a single platform [24-26,28,30-35].

This study was conducted within the AI4HOPE project and used stakeholder input to inform early-stage requirements for a dementia-specific dACP tool. The project is developing a dACP tool intended to extend the early palliative care model established in oncology to dementia care across the full disease trajectory. Building on a prior evidence review and gap analysis, the study aimed to identify and prioritize the components and features that stakeholders consider essential to such a tool. Five research questions (RQs) guided this investigation:

- (RQ1) Which components do ACP stakeholders, and people with dementia in particular, identify as most critical?
- (RQ2) Which digital caregiver-support features should be prioritized?
- (RQ3) How do priorities differ across people with dementia, informal caregivers, and health care professionals?
- (RQ4) How do ACP, symptom management, and caregiver support relate to one another as components of an integrated design?

- (RQ5) Which health-system integration capabilities and review-frequency preferences are considered most critical for implementation?

Methods

Study Design

This study was conducted as part of the EU-funded project AI4HOPE [51], which seeks to improve the quality of life and care for people with dementia through the use of AI and digital technologies. The present work focuses on establishing design priorities through stakeholder input before tool development and implementation. We adapted a cross-sectional mixed methods design implemented as an online survey to identify and prioritize design requirements for a dementia-specific dACP tool. Quantitative survey items were used to assess the perceived importance of ACP content elements, caregiver-support features, preferred frequency of reviewing and updating the care plan, and the importance of integrating the tool with existing health care systems. Qualitative open-ended questions were included to capture stakeholders' perspectives on the primary purpose of the dACP tool, how the tool should support balancing the person's expressed wishes with caregiver decision-making as dementia progresses, and anticipated implementation challenges. Quantitative and qualitative data were analyzed in parallel and integrated at the interpretation stage to derive actionable design priorities for tool development.

Participants and Recruitment

Data were collected via an online survey administered on the Prolific platform in January and February 2025. Recruitment targeted 3 stakeholder groups relevant to dementia-oriented digital ACP: adults with a self-reported dementia diagnosis, informal caregivers, and health care professionals with experience working with people with dementia and/or providing palliative care. Eligible Prolific users were invited to participate through the platform, and interested individuals accessed the study link and reviewed study information prior to beginning the survey. The survey required approximately 15 minutes to complete. Eligibility was set using Prolific and was group-specific:

- Health care professionals were eligible if they currently resided in one of the following countries: Ireland, Germany, France, Spain, Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Greece, Hungary, Iceland, Italy, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, or Sweden, and if their employment sector within medicine/health care was doctor, nurse, psychologist, or social worker.
- Persons with dementia were eligible if they currently resided in one of the following countries: Ireland, Germany, France, Spain, Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Greece, Hungary, Iceland, Italy, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, or Sweden and indicated yes to the prescreener "mild cognitive impairment/dementia."
- Caregivers were eligible if they currently resided in one of the following countries: Ireland, Germany, France, Spain, Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, Greece, Hungary, Iceland, Italy, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Slovakia, Slovenia, or Sweden and indicated yes to "informal/unpaid caring responsibilities."

The final sample consists of 232 participants (118 male, 111 female, 2 other, and 1 individual who preferred not to disclose their sex) from various European countries and the United States. The caregiver sample consists of 106 individuals (56 male, 48 female, 2 other), whose length of role ranged from 0 to 2 years (n=72, 67.9%) to over 10 years (n=4, 3.8%). Notably, 30.2% (n=32) are caregivers to a person with dementia. To examine whether the heterogeneity of the caregiver sample affected the results, we conducted a sensitivity analysis comparing ratings between caregivers of people with dementia (n=32) and caregivers of people with other conditions. Statistically significant differences were observed for only one item across the full Caregiver Stress Management domain, supporting the decision to report the caregiver group as a whole; full between-group comparisons are provided in Table S1 in Multimedia Appendix 1. The health care professionals sample was made up of 113 individuals (47 male, 66 female), whose experience ranged from 0 to 2 years (n=44, 38.9%) to over 10 years (n=15, 13.3%). This group included physicians (n=42, 37.2%), nurses (n=38, 33.6%), psychologists (n=10, 8.8%), and social workers (n=10, 8.8%). A majority (n=73, 64.6%) of health care professionals reported working with patients diagnosed with dementia or those receiving palliative care. The sample of individuals with dementia consisted of 13 individuals (8 male, 4 female, 1 did not wish to answer), whose mean age was 34.46 (SD 14.39; min=18, max=61) years. They reported different dementia diagnoses, including frontotemporal dementia (n=1, 7.69%), poststroke dementia (n=1, 7.69%), Lewy body dementia (n=1, 7.69%), Parkinson disease (n=1, 7.69%), mild dementia (n=2, 15.38%), slight memory loss (n=1, 7.69%), or other cognitive impairments (n=2, 15.38%).

Ethical Considerations

After consultation with the Commission for Ethics in Research at the Faculty of Arts, University of Maribor, formal ethics approval was deemed unnecessary because the study posed negligible risk to participants, in accordance with the commission's guidelines [52]. Accordingly, no formal ethics approval was sought. The study was conducted in accordance with the guidelines of the Commission for Ethics in Research at the Faculty of Arts, University of Maribor. Before beginning the online survey, participants received information about the study and provided informed consent. Participation was voluntary, and participants were free to decide whether to take part. No directly identifying information was collected. Open-ended survey responses were

deidentified before qualitative analysis, and data confidentiality was maintained throughout the research process. Only deidentified responses were used for the qualitative analysis, including the preliminary, LLM-assisted development of the codebooks. No foreseeable physical or psychological harms were identified. Participants received £4.50 (£1=US $1.32 as of November 16, 2026) as compensation for completing the online survey.

Measures

Overview

The survey included quantitative rating items and open-ended questions designed to elicit stakeholder priorities for a dementia-specific dACP tool. Survey items were developed specifically for this study because existing ACP instruments did not capture the combination of dementia-specific ACP content and digital tool functionality required for early, iterative planning across the dementia trajectory. An expert panel within the AI4HOPE consortium (including neurology, palliative care, medicine, AI, and social science expertise) generated an initial pool of candidate items based on the project's design goals for a dementia-specific dACP tool. The panel iteratively refined items for clarity, relevance to dementia care, and suitability for an online survey format, resulting in two quantitative item sets: (1) elements of ACP tailored to dementia and (2) digital features intended to support caregiver stress management.

ACP Content Elements (Primary Quantitative Outcome)

Participants rated the importance of 12 elements of an advance care plan tailored to people with dementia (eg, decisions about future medical treatments and interventions, appointment of a health care proxy or power of attorney, strategies for maintaining quality of life as the disease progresses). Items were rated on a 7-point Likert scale ranging from 1 ("not important") to 7 ("essential").

Caregiver-Support Features (Primary Quantitative Outcome)

Participants rated the importance of 10 potential dACP features intended to support caregivers in managing dementia-related stress (eg, tips for managing challenging behaviors associated with dementia; self-assessment tools for caregiver stress and burnout; connection to professional mental health support services). Items were rated on the same 7-point Likert scale (1=not important to 7=essential).

Review/Update Preferences and Integration (Secondary Quantitative Outcomes)

Participants indicated how often the dACP tool should prompt review and potential updates of the care plan using a 5-option response scale (every 3 months, every 6 months, annually, only when prompted by the patient or caregiver, other). Participants also rated the importance of integrating the dACP tool with existing health care systems on a 7-point Likert scale (1=not important to 7=essential).

Open-Ended Questions (Qualitative Outcomes)

At the beginning of the survey, participants answered an open-ended question on what they believed should be the primary purpose of the dACP tool. Moreover, participants were also asked to provide open-ended responses regarding (1) how the dACP tool should balance respecting the person with dementia's expressed wishes with the need for caregiver decision-making as the disease progresses and (2) the biggest anticipated challenges in implementing a dACP tool for people with dementia.

Quantitative Analysis

Quantitative analyses were conducted in SPSS (version 29; IBM Corp). After data cleaning, we included all respondents who met eligibility criteria and completed the survey, resulting in a final analytic sample with no missing data. We summarized item distributions using descriptive statistics and examined associations among central variables using correlation coefficients selected based on distributional assumptions.

For dimensionality reduction, we conducted principal component analyses (PCA) separately for (1) ACP content items and (2) caregiver-support feature items, using oblique rotation (direct oblimin) given the conceptual relatedness of domains. Sampling adequacy was evaluated using the Kaiser-Meyer-Olkin (KMO) statistic and the Bartlett test of sphericity. The number of components retained was guided by eigenvalues of greater than 1 and inspection of the scree plot, and components were interpreted based on rotated loadings. Component scores were computed as mean component scores based on item loadings and used for subsequent analyses.

Group differences between people with dementia, caregivers, and health care professionals were examined using ANOVA. For update frequency, we excluded responses that could not be ordered on the provided scale (eg, "only when prompted" and "other") from ANOVA, as in the primary analysis plan.

Qualitative Analysis

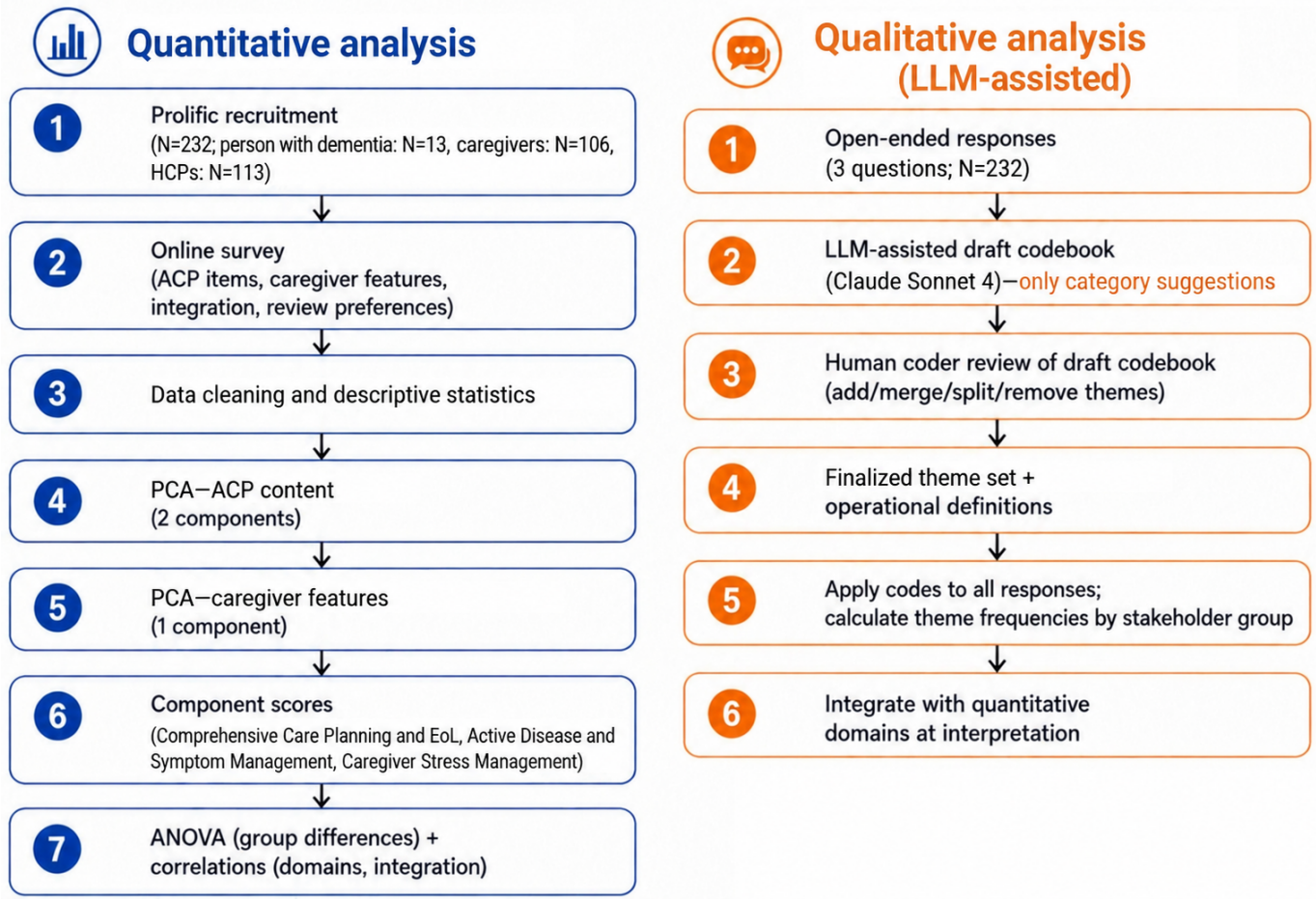
We analyzed responses to the open-ended survey questions using a data-driven thematic analysis approach to identify recurring needs, expectations, and concerns regarding a dementia-specific dACP tool. Thematic analysis was selected because it is well suited to concise, heterogeneous survey responses and does not presuppose extended narratives required by other qualitative approaches [53]. An inductive orientation was adopted given the absence of a validated coding framework for stakeholder perspectives on dementia-specific dACP design, allowing priorities to emerge directly from the data. This approach also permits systematic categorization and descriptive frequency quantification necessary for cross-group comparison. LLM-assisted draft codebook generation was incorporated to manage response volume (N=232 across 3 open-ended questions), while dual-coder manual verification ensured that all interpretive decisions remained with human researchers, in line with

emerging guidance on responsible LLM use in qualitative health research [54].

All open-ended responses were exported, deidentified, and cleaned (removal of empty responses and nonsubstantive entries). Responses to each of the 3 open-ended questions were submitted separately to Claude Sonnet 4 (Anthropic) [55] using a structured, constrained prompt. The prompt instructed the model to (1) read all responses to the given question, (2) identify recurring conceptual categories, (3) produce a concise label and brief operational definition for each candidate theme, and (4) provide illustrative groupings of similar response excerpts per theme. The LLM was explicitly instructed not to interpret, generalize beyond, or paraphrase the source responses. Its output was treated solely as a preliminary draft codebook and was used as a structured synthesis to accelerate initial organization of a large response set. No analytic claims were drawn from it directly [56].

Afterward, a researcher (AM or IM) reviewed the LLM-generated draft codebook against the full set of original participant responses for each question. They applied iterative edits to the codebook, including removing themes not sufficiently grounded in the data, merging conceptually overlapping themes, splitting overly broad themes into more specific categories, and adding themes absent from or underspecified in the draft. After independent review, coders met to reconcile disagreements through discussion and consensus, producing a finalized theme set with agreed operational definitions. The wording of theme labels was further refined for alignment with established terminology in ACP and palliative dementia care (eg, distinguishing documentation and legal functions from decision-support functions, distinguishing usability barriers from disease-progression-related adaptation requirements). The finalized codebook was then applied to all responses, and descriptive frequencies (proportion of respondents per stakeholder group mapping to each theme) were calculated to support cross-group comparison. The full theme set is provided in Multimedia Appendix 1. Themes are reported in the *Results* section as the most frequently occurring categories per question and stakeholder group, with the full set of themes provided in Multimedia Appendix 1. Visual presentation of analysis workflow can be seen in Figure 1.

Figure 1. Study and mixed-methods analysis workflow. ACP: advance care planning; EoL: end of life; HCP: health care professional; LLM, large language model; PCA: principal component analysis.



Results

Reducing the Dimensionality of Questionnaire Items

Most Important Elements of an Advance Care Plan for People With Dementia

A PCA was conducted on 11 items with oblique rotation (direct oblimin) to reduce the number of responses regarding the most important elements of ACP for individuals with dementia into main components. The KMO measure confirmed the adequacy of the sample for the analysis (KMO=0.83). The Bartlett test of sphericity was significant (χ^2_{55}=596.11; P<.001), indicating that correlations between items were sufficient for component extraction.

An initial examination of data was done to determine the number of main components present. Using Kaiser's criterion (retaining components with eigenvalues >1), 2 components were extracted, together accounting for 46.83% of the total variance. The scree plot further supported a 2-component solution, which was also easily interpretable. Rotated component loadings are presented in Table 1. Component 1 includes items related to Comprehensive Care Planning and End-of-Life Preparation referring to long-term, anticipatory planning, such as values, legal arrangements, and end-of-life preferences, and component 2 includes items related to Active Disease and Symptom Management referring to active, ongoing, day-to-day clinical management of symptoms and crises.

Table 1. Rotated component loadings for most important elements of advance care planning (ACP).

Elements of ACP	Rotated component loadings	
	Comprehensive Care Planning and End-of-Life Preparation	Active Disease and Symptom Management
1. Decisions about future medical treatments and interventions	0.58[a]	0.07
2. Appointment of health care proxy or power of attorney	0.66[a]	–0.03
3. Strategies for maintaining quality of life as the disease progresses	0.06	0.56[a]
4. Monitoring and symptom management	–0.02	0.77[a]
5. Management of behavioral symptoms associated with dementia	0.003	0.78[a]
6. Crisis prevention and management strategies	–0.01	0.74[a]
7. Guidance on when to transition to palliative care	0.65[a]	0.07
8. Wishes for memory preservation and legacy (eg, recording life stories)	0.51[a]	–0.02
9. Preferences for end-of-life care	0.66[a]	0.16
10. Financial and legal planning considerations	0.70[a]	0.04
11. Cultural or spiritual preferences	0.75[a]	–0.15

[a]This value indicates the highest rotated component loading for each item, identifying the component with which that item is most strongly associated.

Features to Assist Caregivers in Managing Stress

A separate PCA was conducted on 10 items concerning features that may assist caregivers in managing stress, also using oblique rotation (direct oblimin). The KMO measure indicated sampling adequacy (KMO=0.89), and the Bartlett test of sphericity was significant (χ^2_{45}=823.08; P<.001), confirming the suitability of data for component extraction. According to Kaiser's criterion, one component, which accounted for 46.32% of the variance, was identified. Rotated component loadings are shown in Table 2. The 10 items loaded on a single component, labeled Caregiver Stress Management referring, which encompasses features designed to help caregivers manage stress, including access to professional mental health support, educational resources, and opportunities to build support networks.

Table 2. Rotated component loadings for assisting the management of caregiver stress.

Caregiver stress management features	Rotated component loadings for caregiver stress management
1. Self-assessment tools for caregiver stress and burnout	0.65
2. Personalized stress management techniques and resources	0.75
3. Information on respite care options and how to access them	0.70
4. Guided meditation or relaxation exercises	0.62
5. Tips for managing challenging behaviors associated with dementia	0.61
6. Resources for building a support network (eg, support groups, community services)	0.66
7. Time management and organization tools for caregiving tasks	0.64
8. Educational content on self-care and setting boundaries	0.71

Caregiver stress management features	Rotated component loadings for caregiver stress management
9. Connection to professional mental health support services	0.70
10. Reminders for caregiver's own health check-ups and appointments	0.75

Comparisons of Central Variables Among Caregivers, Health Care Professionals, and People With Dementia

ANOVA was used to assess group differences across central variables, and the results are presented in Table 3.

Table 3. Mean and SD values for central variables, and ANOVA results.

Variable	Caregivers, mean (SD)	Health care professionals, mean (SD)	People with dementia, mean (SD)	ANOVA	
				F test (*df*)	η^2
Comprehensive Care Planning and End-of-Life Preparation[a]	3.45 (0.59)	3.48 (0.58)	3.60 (0.43)	0.40 (2, 229)	0.004
Active Disease and Symptom Management[b]	4.33 (0.46)	4.33 (0.58)	4.13 (0.56)	0.85 (2, 229)	0.007
Caregiver Stress Management[c]	3.74 (0.59)	3.76 (0.61)	3.80 (0.74)	0.07 (2, 229)	0.001
Importance of integration	6.12 (0.95)	6.18 (0.97)	6 (1.47)	0.22 (2, 229)	0.002
Frequency of review and updates[d]	1.55 (0.61)	1.55 (0.58)	1.5 (0.52)	0.04 (2, 229)	<0.001

[a]Min=1.45, max=4.52.
[b]Min=1.95, max=4.98.
[c]Min=1.07, max=4.75.
[d]Analysis was performed on a smaller sample (n=193), as values 4 ("only when prompted by patient or caregiver," n=21) and 5 ("other," n=18) were excluded from ANOVA. Mean component scores were calculated using the following equation: component mean score = ((item 1 × component loading 1) + (item 2 × component loading 2) + …(item n × component loading n))/n.

ANOVA indicated no statistically significant differences among group means; therefore, further analyses were done on the full sample. Mean and SD values for all items by group can be found in Table S2 (Multimedia Appendix 1).

Within the Comprehensive Care Planning and End-of-Life Preparation component, the item "Decisions about future medical treatments and interventions" was recognized as the most important (mean 5.84, SD 1.26), while the item "Cultural or spiritual preferences" was the least important (mean *M* 4.80, SD 1.49). In the Active Disease and Symptom Management component, the item rated as the most important (mean 6.32, SD 1.01) is "Strategies for maintaining quality of life as the disease progresses," while "Crisis prevention and management strategies" was least important (mean 5.90, SD 1.10). In the Caregiver Stress Management component, the item "Tips for managing challenging behaviors associated with dementia" was recognized as the most important (mean 6.04, SD 1.13), while the item "Guided meditation or relaxation exercises" was the least important (mean 4.92, SD 1.53; see Table S1 for specific mean values in Multimedia Appendix 1).

Associations Between Central Variables

For the purpose of assessing the strength and direction of association between central variables, correlation coefficients were calculated (presented below in Table 4).

Table 4. Correlations between central variables.

Variable	1	2	3	4	5
Comprehensive Care Planning and End-of-Life Preparation	—[a]	—	—	—	—
Active Disease and Symptom Management	0.43[b]	—	—	—	—
Caregiver Stress Management	0.51[b]	0.52[b]	—	—	—
Importance of integration	0.06	0.24[b]	0.23[b]	—	—
Frequency of review and updates	–0.05	0.05	–0.05	0.06	—

[a]Not applicable.
[b]*P*<.001.

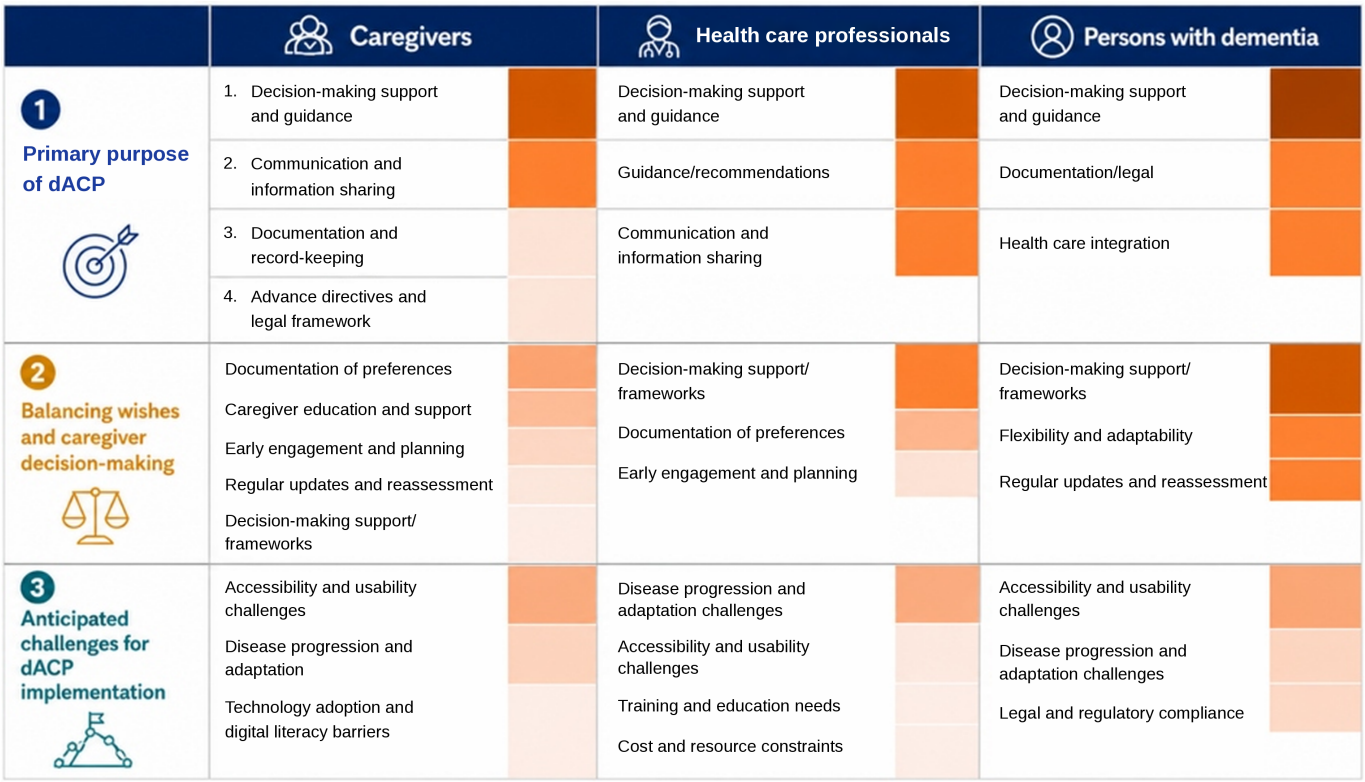
The Comprehensive Care Planning and End-of-Life Preparation component is statistically significantly positively correlated with both the Active Disease and Symptom Management component and the Caregiver Stress

Management component. Additionally, the Active Disease and Symptom Management component is statistically significantly correlated with Caregiver Stress Management and Importance of integration of dACP in the health care system. Finally, Caregiver Stress Management is also statistically significantly correlated with the Importance of integration variable.

Exploring Qualitative Responses on dACP

Answers of the 3 questions were categorized into 8 to 25 main themes for each of the questions. The most prominent 3 (or more, in cases of same frequency of mentions of the third) themes identified are reported in this subsection (all extracted themes can be found in Table S3 in Multimedia Appendix 1). For visual presentation of the main results, see Figure 2.

Figure 2. Stakeholder qualitative themes on purpose, balancing wishes, and anticipated challenges. Darker shading indicates higher mention frequency within each stakeholder group. dACP: digital advance care planning.



Primary Purpose of dACP

As the primary purpose of dACP, caregivers identified Decision-Making Support and Guidance (n=54, 50.94%), which refers to guiding care choices for both patients and caregivers based on the individual's preferences and needs; Communication and Information Sharing (n=38, 35.85%), referring to enabling sharing capabilities with family members and health care providers, as well as facilitating information exchange within the health care system; Documentation and Record-Keeping (n=21, 19.81%), referring to automated and intelligent filing of documents to maintain organized records of care preferences and plans; and Advanced Directives and Legal Framework (n=21, 19.81%), referring to creating and managing legally binding advanced directives that formalize the patient's wishes for future care.

Health care providers most prominently identified Decision-Making Support and Guidance (n=61, 54.46%), referring to guiding care choices for health care professionals and caregivers based on the patient's individual preferences; Guidance/Recommendations (n=52, 46.43%), which refers to providing care recommendations and guidance for managing daily activities, pain assessment, medication reminders, and symptom monitoring; and Communication and Information Sharing (n=42, 37.5%), referring to sharing capabilities including advanced directives, facilitating general communication between patients, health care professionals, and caregivers to ensure everyone is informed.

Finally, persons with dementia also identified Decision-Making Support and Guidance (n=10, 76.92%), referring to providing support and guidance to help individuals make informed decisions about care; Documentation/Legal (n=6, 46.15%), referring to managing advanced directives and legal documentation of care preferences in a formalized manner; and Health Care Integration (n=5, 38.46%), which refers to enabling information sharing within the health care system and coordinating with health care providers for comprehensive medical care management.

Balancing the Expressed Wishes of Patients With Dementia With the Need for Caregiver Decision-Making

When it comes to balancing patient wishes with caregiver decision-making, caregivers have identified the following themes as most prominent: Documentation of Preferences (n=29, 27.36%), referring to clear documentation of all relevant patient information and preferences within the tool to ensure nothing is forgotten or overlooked; Caregiver Education and Support (n=26, 23.21%), referring to providing caregivers with guidance through the tool's repository of patient preferences, reminding them of the patient's wishes, and offering prompts for consulting with health care professionals; Early Engagement and Planning (n=21, 19.81%), referring to initiation of ACP discussions and documentation early in the disease process; Regular Updates and Reassessment (n=21, 19.81%), referring to continuous monitoring of the patient's condition, tracking disease progression, and prompting updates to care plans as needed through reminders and adjustments; and Decision-Making Support/Frameworks (n=21, 19.81%), referring to implementation of flexible frameworks such as gradual transfer of decision-making authority from patient to caregiver as the disease progresses, using weighted approaches that consider multiple factors.

Health care professionals most prominently identified Decision-Making Support/Frameworks (n=42, 37.5%), referring to balancing different perspectives with patient wishes as the priority while not limiting necessary care, providing alternatives and recommendations that weigh pros and cons using algorithms based on human and patient rights, and distinguishing between essential end-of-life needs vs preferences that can only be respected if they do not conflict with care needs; Documentation of Preferences (n=23, 20.54%), referring to sharing documented patient wishes and key information with caregivers and health care professionals to ensure everyone is aligned and informed; and Early Engagement and Planning (n=19, 16.96%), which refers to encouraging early conversations and relying primarily on wishes expressed before progression of the disease, documenting what the patient stated when still cognitively able to do so.

Finally, persons with dementia also identified Decision-Making Support/Frameworks (n=7, 53.85%), referring to providing frameworks that help both patients and caregivers understand their positions and roles at any given time as the disease progresses; Flexibility and Adaptability (n=4, 30.77%), which refers to maintaining adaptability in the tool's approach to accommodate changing circumstances and individual patient needs; and Regular Updates and Reassessment (n=4, 30.77%), referring to ensuring continuous monitoring and assessment of the patient's condition and care preferences over time.

Biggest Anticipated Challenges in Implementing a dACP Tool

As the biggest anticipated challenges in implementing a dACP tool, caregivers most prominently identified Accessibility and Usability Challenges (n=36, 33.96%), referring to difficulties with understanding the tool in later disease stages, adapting it to individual patients, and overcoming basic technological unfamiliarity, particularly for patients who may struggle with using technology; Disease Progression and Adaptation Challenges (n=26, 23.21%), referring to the tool having to adapt as cognitive status changes over time and need for quick implementation in order for the tool to be useful throughout the disease trajectory; and Technology Adoption and Digital Literacy Barriers (n=20, 18.87%), which refers to overall user adoption challenges, including the need for training and support, particularly given caregiver burden concerns.

Health care professionals identified Disease Progression and Adaptation Challenges (n=25, 22.32%), referring to adaptation to disease progression, keeping documentation updated, predicting future problems and decisions, and ensuring rapid implementation before cognitive abilities decline significantly; Accessibility and Usability Challenges (n=22, 19.64%), which refers to ensuring the tool works for diverse patient groups with varying needs, is easy to use, and doesn't create barriers where some people cannot use it effectively; Training and Education Needs (n=20, 17.86%), referring to providing adequate training and education for all users to effectively utilize the tool; and Cost and Resource Constraints (n=20, 17.86%), referring to managing time as a resource, implementation costs, and the human resources needed for development and ongoing support.

Lastly, persons with dementia also identified Accessibility and Usability Challenges (n=6, 46.15%), which refers to ensuring appropriate system design and clear communication that is suitable for individuals experiencing cognitive decline; Disease Progression and Adaptation Challenges (n=4, 30.77%), which addresses how the tool adapts as cognitive abilities decline over time; and Legal and Regulatory Compliance (n=4, 30.77%), referring to navigating legal and ethical concerns, along with regulatory requirements for such a health care tool.

Discussion

Principal Findings

The presented mixed methods study identified stakeholder-informed priorities for a dementia-specific dACP tool that supports ACP as a longitudinal, person-centered process. Across quantitative and qualitative findings, stakeholders prioritized maintenance of quality of life, decision-making support, caregiver guidance, and integration with health care systems. These priorities are consistent with concerns that conventional ACP can become overly focused on documentation and treatment decisions, rather than supporting values-

based decisions about living with serious illness [12,14,57,58].

The findings also require cautious interpretation in relation to the group of people with dementia. This subgroup comprised 13 self-identified participants, with a mean age of 34.46 (SD 14.39; range 18-61) years and heterogeneous self-reported diagnoses, including both dementia subtypes and broader cognitive-concern labels. The age profile differs substantially from the epidemiology of even young-onset dementia, for which prevalence increases sharply across adulthood, from approximately 1.1 per 100,000 among adults aged 30 to 34 years to 77.4 per 100,000 among those aged 60 to 64 years [59]. Confirmed young-onset dementia cohorts also report a substantially later mean age at diagnosis and diagnostic delays of approximately 3.6 years [60]. Together with recruitment through a Prolific prescreener rather than clinical confirmation, these characteristics limit the subgroup's representativeness of clinically diagnosed dementia populations. The findings from this group should therefore be considered hypothesis-generating, rather than confirmatory.

ACP and Caregiver Priorities

With respect to RQ1, which examined stakeholders' priorities for comprehensive ACP in dementia, the ACP PCA identified 2 related domains, Comprehensive Care Planning and End-of-Life Preparation and Active Disease and Symptom Management, which together explained 46.83% of variance. The highest-rated item was maintaining quality of life as dementia progressed (mean 6.32, SD 1.01), followed by decisions about future medical treatments and interventions (mean 5.84, SD 1.26). This pattern indicates that stakeholders considered ACP in dementia to encompass both prospective planning and support for day-to-day clinical needs, including symptoms, behavioral changes, and crises.

The qualitative findings further reinforced this interpretation. Decision-making support and guidance was the most frequently identified primary purpose of a dACP tool among caregivers (n=54, 50.94%), health care professionals (n = 61, 54.46%), and people with dementia (n=10, 76.92%). Communication and information sharing was also prominent among caregivers (n=38, 35.85%) and professionals (n=42, 37.50%), whereas people with dementia additionally identified documentation and legal functions (n=6, 46.15%) and health care integration (n=5, 38.46%) as central. These findings support a view of ACP as an iterative, capacity-sensitive communication process involving the person, family caregivers, and health care professionals, rather than a one-time advance-directive exercise [9,12,15-18,57,58].

Regarding RQ2, which examined priorities for digital caregiver support, caregiver-support functions formed one Caregiver Stress Management domain, accounting for 46.32% of variance. Guidance for managing challenging behaviors was the highest-rated caregiver-support feature (mean 6.04, SD 1.13). When considering how a dACP tool should balance the person's wishes with increasing caregiver responsibilities, caregivers emphasized documentation of preferences (n=29, 27.36%); education and support (n=26, 23.21%); and early engagement, regular reassessment, and decision-making frameworks (each n=21, 19.81%). These results indicate that caregivers need support not only for managing dementia-related symptoms but also for accessing and interpreting the person's values as responsibility for decisions evolves. This is aligned with palliative-care models that include caregiver well-being, psychosocial support, and shared decision-making as core elements of care [15,21,28,36,37].

Stakeholder Perspectives and Domains

For RQ3, which examined differences in priorities across people with dementia, caregivers, and health care professionals, ANOVA identified no statistically significant differences between groups on the central quantitative variables. However, this should not be interpreted as definitive evidence of stakeholder agreement. The small and demographically atypical dementia subgroup reduced statistical power to detect between-group differences and limits the generalizability of subgroup findings. The observed overlap in priorities should therefore be interpreted as preliminary, providing candidate shared priorities for subsequent co-design and validation in larger, clinically verified, and more balanced samples.

Addressing RQ4, which examined relationships among ACP, symptom management, caregiver support, and integration, the correlation analyses indicated that stakeholder priorities spanned connected care domains. Comprehensive Care Planning and End-of-Life Preparation was positively associated with Active Disease and Symptom Management (r=0.43) and Caregiver Stress Management (r=.51). Active Disease and Symptom Management was associated with Caregiver Stress Management (r=0.52) and perceived importance of health system integration (r=.24). Caregiver Stress Management was also associated with integration importance (r=0.23; all P<.01). However, these results do not establish causal relationships, but they do suggest that stakeholders regarded prospective planning, current symptom needs, caregiver capacity, and integration with services as interdependent elements of dementia care.

This interpretation is further supported by qualitative findings. When discussing changing decision-making responsibilities, people with dementia most often emphasized structured decision-making frameworks (n=7, 53.85%), flexibility and adaptability (n=4, 30.77%), and regular updates and reassessment (n=4, 30.77%). Health care professionals similarly prioritized decision-making frameworks (n=42, 37.50%), documentation of preferences (n=23, 20.54%), and early engagement and planning (n=19, 16.96%). These findings highlight that a clinically useful ACP process must preserve the person's expressed values while enabling transparent, context-sensitive involvement of caregivers and professionals as decisional capacity and care needs evolve [15,16,18,20,57,61,62].

Implementation and Review

Finally, addressing RQ5, which examined integration and care-plan review preferences, health system integration was rated highly important across all groups, with means ranging

from 6.00 (SD 1.47) among people with dementia to 6.18 (SD 0.97) among health care professionals. Integration importance was associated with both symptom-management and caregiver-support domains, suggesting that stakeholders considered an isolated tool insufficient for supporting dementia care. Participants also preferred regular review, with mean scores of 1.50 to 1.55 (SD 0.52-0.61) on the ordered review-frequency scale, and regular updates and reassessment was a prominent qualitative theme.

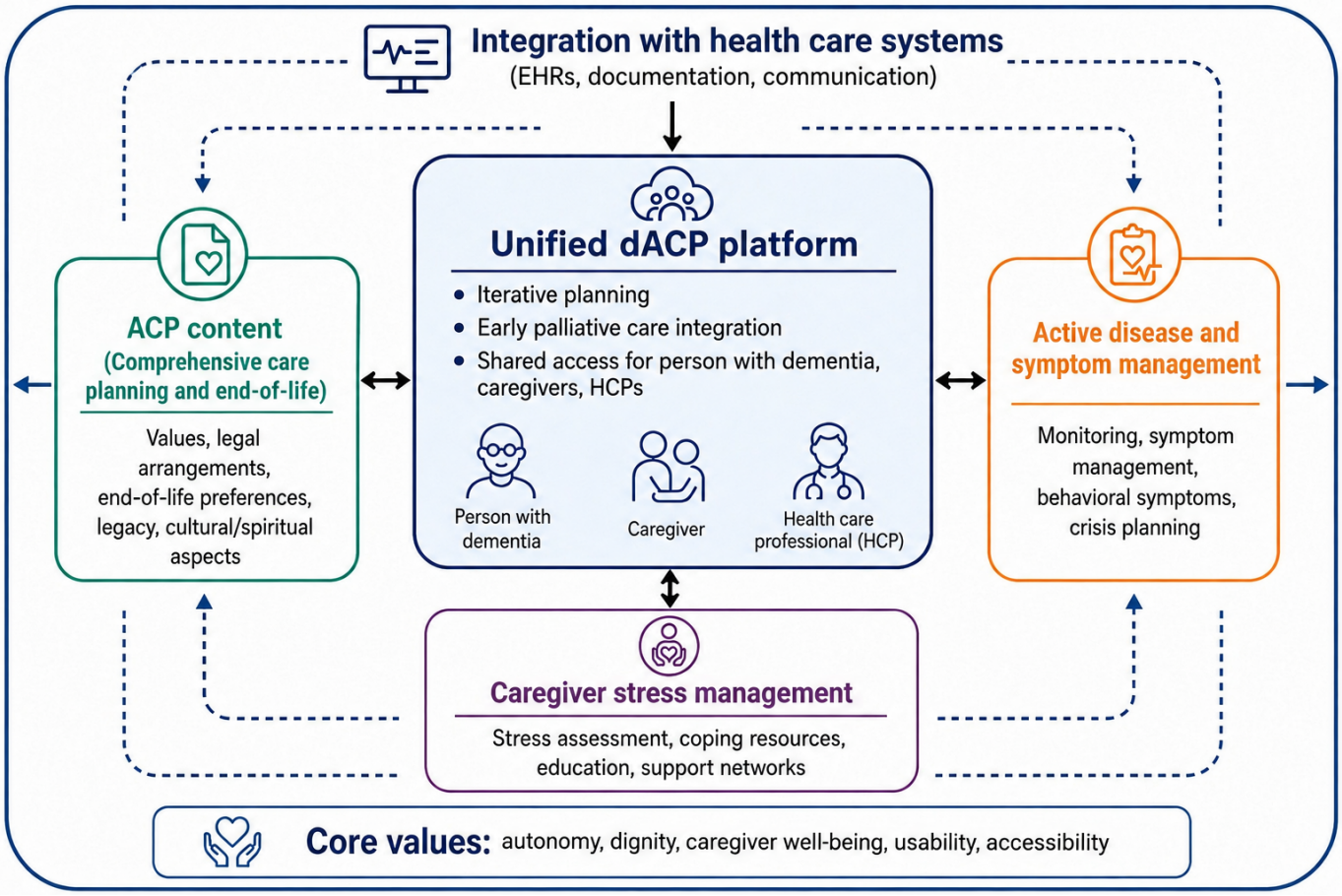
Implementation barriers reflected the requirements of an aging population with progressive cognitive impairment. Accessibility and usability concerns were raised by 33.96% (n=36) of the caregivers, 19.64% (n=22) of the health care professionals, and 46.15% (n=6) of the people with dementia. Disease-progression and adaptation concerns were identified by 23.21% (n=26), 22.32% (n=25), and 30.77% (n=4), respectively. These findings emphasize that digital ACP requires more than electronic preference documentation: it must remain usable as cognitive abilities change; be understandable to caregivers; and fit care pathways that span home, community, primary, specialist, and long-term care settings [15,20,24-26,35,61-63].

Interoperability should be treated as a staged implementation objective, initially prioritizing secure, role-appropriate access to current preferences and later addressing structured exchange and governance within local clinical workflows. Although HL7 FHIR offers a relevant technical standard, successful integration also depends on clear responsibility for reviewing preferences at clinically meaningful transitions [61,63-68].

Implications for Design

The results support a value-sensitive approach to dACP development, as value-sensitive design combines conceptual investigation of values and stakeholders, empirical investigation of user experiences, and technical translation into system features [69,70]. Based on the facilitated methodology, this study primarily focuses on the conceptual and empirical phases by identifying values and needs that should guide later co-design, prototyping, usability testing, and implementation research. Figure 3 summarizes the resulting conceptual design priorities.

Figure 3. Conceptual design priorities for unified dementia-specific digital advance care planning (dACP) platform. ACP: advance care planning; EHR: electronic health record; HCP: health care professional.



As outlined in Figure 3, the main identified conceptual design priorities include the following:

- Autonomy and self-determination: Enable values clarification and iterative decision support, not only static preference recording [9,12,14-16].
- Dignity and continuity: Link current symptom and behavioral needs with care preferences across disease progression [15,16,18,27,57,62].
- Caregiver well-being: Include practical behavioral guidance, caregiver stress support, and access to professional resources as core functions [15,21,28,36,37].
- Accessibility: Use adaptive, low-burden interactions that accommodate cognitive decline and differing digital literacy [35,40,44,45].
- Proxy accountability: Support traceable preference updates, decision rationales, and transparent transitions in decision-making responsibility [14,16,63].
- Care continuity: Enable structured sharing of current preferences across care settings and professionals [24-26,35,61,63].
- Iterative review: Trigger review after clinically or socially meaningful change rather than relying only on fixed schedules [15,20,61].

Limitations

Several limitations require consideration when interpreting our findings. The people-with-dementia subgroup was small (n=13), younger than expected for a clinically representative dementia population, and recruited on the basis of a self-reported Prolific prescreener. Therefore, it may include individuals with self-identified cognitive concerns rather than clinically verified dementia, and the findings from this subgroup should not be generalized to the broader dementia population [59,60,71-73]. The caregiver sample was also heterogeneous; however, only one of 10 Caregiver Stress Management items differed significantly between caregivers of people with dementia and caregivers of people with other conditions, suggesting that pooling caregivers did not materially alter the central design priorities.

The international sample did not ensure broad cultural representation, and the cross-sectional design captured preferences at one time point despite the changing needs associated with dementia. Future studies should use longitudinal, culturally diverse, and clinically based recruitment pathways, with larger and more balanced stakeholder samples [15,20,47,62]. The study-specific measures require further psychometric evaluation, and their relation to clinical, caregiver, and implementation outcomes remains uncertain [31].

Finally, exclusive online recruitment may have underrepresented people with advanced dementia, limited digital access, lower digital literacy, or substantial caregiver burden. Online self-selection may also have favored people with prior interest in ACP, potentially increasing importance ratings. Although Prolific can support high-quality data collection, data quality depends on validation procedures and study design [71-73]. The LLM was restricted to draft-codebook generation, with all coding, theme refinement, and interpretation performed by human researchers; nevertheless, LLM-assisted qualitative methods can reproduce biases or introduce data-distant conceptual framings [54]. Future studies should assess real-world acceptability, equity, clinical workflow impact, and cost-effectiveness once dACP is implemented in routine care [33,34].

Conclusions

This mixed methods study identified stakeholder-informed priorities for a dementia-specific dACP tool centered on quality-of-life maintenance, decision-making support, caregiver guidance, health-system integration, and context-sensitive review. The findings support a longitudinal, person-centered approach that complements communication among people with dementia, caregivers, and health care professionals. However, because the dementia subgroup was small, demographically atypical, and based on self-reported eligibility, apparent cross-group convergence should be interpreted as preliminary. Future work should use clinically verified and more representative samples to co-design, test, and evaluate the feasibility, equity, implementation, and clinical impact of dACP in routine dementia care.

Generative AI Use

A large language model was used to assist with rapid synthesis and to propose candidate themes, but final coding decisions, theme boundaries, and interpretation were determined by the research team through manual review of the original responses. In addition, the GPT-5.2 (OpenAI) and Gemini 3 (Google) were used for language editing (eg, grammar and clarity improvements) of manuscript text. All information generated by the models was thoroughly reviewed by the authors.

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Data Availability

The datasets generated and/or analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

Conceptualization: IM
Data curation: AM, IM
Formal analysis: AM, US
Funding acquisition: IM
Methodology: IM, US, AM
Supervision: US
Writing – original draft: IM, US, AM
Writing – review & editing: AM, US, IM

Conflicts of Interest

None declared.

Multimedia Appendix 1

Caregiver subgroup comparisons, descriptive statistics by stakeholder group and for the full sample, correlations among study variables, and the complete list of qualitative themes with frequencies by stakeholder group and question.
[DOCX File (Microsoft Word File), 64 KB-Multimedia Appendix 1]

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Abbreviations

ACP: advance care planning
dACP: digital advance care planning
KMO: Kaiser-Meyer-Olkin
LLM: large language model
PCA: principal component analysis
RQ: research question

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